# **Complete Summary**

#### **GUIDELINE TITLE**

Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 137-146: cancer and general health screening.

## **BIBLIOGRAPHIC SOURCE(S)**

Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 137-146: cancer and general health screening. Bethesda (MD): Children's Oncology Group; 2006 Mar. 11 p. [45 references]

#### **GUIDELINE STATUS**

This is the current release of the guideline.

This guideline updates a previous version: Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 1.2. 2004 Mar.

## **COMPLETE SUMMARY CONTENT**

SCOPE

METHODOLOGY - including Rating Scheme and Cost Analysis RECOMMENDATIONS

EVIDENCE SUPPORTING THE RECOMMENDATIONS

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS OUALIFYING STATEMENTS

IMPLEMENTATION OF THE GUIDELINE

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IDENTIFYING INFORMATION AND AVAILABILITY DISCLAIMER

## **SCOPE**

# **DISEASE/CONDITION(S)**

General health and common adult onset cancers, including:

- Breast cancer
- Cervical cancer
- Colorectal cancer
- Endometrial cancer
- Lung cancer

- Oral cancer
- Prostate cancer
- Skin cancer
- Testicular cancer

## **GUIDELINE CATEGORY**

Evaluation Prevention Screening

#### **CLINICAL SPECIALTY**

Family Practice
Internal Medicine
Obstetrics and Gynecology
Oncology
Pediatrics
Urology

## **INTENDED USERS**

Advanced Practice Nurses Nurses Physician Assistants Physicians

## **GUIDELINE OBJECTIVE(S)**

- To provide preventive screening recommendations for common adult-onset cancers for survivors of pediatric malignancies
- To increase quality of life and decrease complication-related healthcare costs for pediatric cancer survivors by providing standardized and enhanced followup care throughout the life-span that (a) promotes healthy lifestyles, (b) provides for ongoing monitoring of health status, (c) facilitates early identification of late effects, and (d) provides timely intervention for late effects

## **TARGET POPULATION**

Asymptomatic survivors of childhood, adolescent, or young adult cancers who present for routine exposure-related medical follow-up

# INTERVENTIONS AND PRACTICES CONSIDERED

Thorough history and physical examination and targeted screening evaluations

## **MAJOR OUTCOMES CONSIDERED**

Not stated

## **METHODOLOGY**

# METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

## DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Pertinent information from the published medical literature over the past 20 years (updated as of October 2005) was retrieved and reviewed during the development and updating of these guidelines. For each therapeutic exposure, a complete search was performed via MEDLINE (National Library of Medicine, Bethesda, MD). Keywords included "childhood cancer therapy," "complications," and "late effects," combined with keywords for each therapeutic exposure. References from the bibliographies of selected articles were used to broaden the search.

#### NUMBER OF SOURCE DOCUMENTS

Not stated

# METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus (Committee)

#### RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

#### METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review

#### **DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE**

Not stated

## METHODS USED TO FORMULATE THE RECOMMENDATIONS

**Expert Consensus** 

# DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

In 2002, the leadership of the Children's Oncology Group Late Effects Committee and Nursing Discipline appointed a 7-member task force, with representation from the Late Effects Committee, Nursing Discipline, and Patient Advocacy Committee. The task force was convened to review and summarize the medical literature and

develop a draft of clinical practice guidelines to direct long-term follow-up care for pediatric cancer survivors. The task force followed a modified version of the guideline development process established by the National Comprehensive Cancer Network (NCCN), integrating available literature with expert opinion using reiterative feedback loops.

The original draft went through several iterations within the task force prior to initial review. Multidisciplinary experts in the field, including nurses, physicians (pediatric oncologists and other subspecialists), patient advocates, behavioral specialists, and other healthcare professionals, were then recruited by the task force to provide an extensive, targeted review of the draft, including focused review of selected guideline sections. Revisions were made based on these recommendations. The revised draft was then sent out to additional multidisciplinary experts for further review. A total of 62 individuals participated in the review process. The guidelines subsequently underwent comprehensive review and scoring by a panel of experts in the late effects of pediatric malignancies, comprised of multidisciplinary representatives from the COG Late Effects Committee.

## **Revisions**

In order to keep the guidelines current and clinically meaningful, the COG Late Effects Committee organized 18 multi-disciplinary task forces in March 2004. These task forces were charged with the responsibility for monitoring the medical literature in regard to specific system-related clinical topics relevant to the guidelines (e.g., cardiovascular, neurocognitive, fertility/reproductive), providing periodic reports to the Late Effects Committee, and recommending revisions to the guidelines and their associated health education materials and references (including the addition of therapeutic exposures) as new information became available. Task force members were assigned according to their respective areas of expertise and clinical interest. A list of these task forces and their membership is included in the "Contributors" section of the original guideline document. The revisions incorporated into the current release of these guidelines (Version 2.0 – March 2006) reflect the contributions and recommendations of these task forces.

All revisions proposed by the task forces were evaluated by a panel of experts, and if accepted, assigned a score. Proposed revisions that were rejected by the expert panel were returned with explanation to the relevant task force chair. If desired, task force chairs were given an opportunity to respond by providing additional justification and resubmitting the rejected task force recommendation(s) for further consideration by the expert panel. A total of 34 sections and 9 Health Links were added to Version 2.0 of these guidelines.

#### RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

#### **COST ANALYSIS**

A formal cost analysis was not performed and published cost analyses were not reviewed.

## **METHOD OF GUIDELINE VALIDATION**

External Peer Review Internal Peer Review

## **DESCRIPTION OF METHOD OF GUIDELINE VALIDATION**

The initial version of the guidelines (Version 1.0 – Children's Oncology Group Late Effects Screening Guidelines) was released to the Children's Oncology Group (COG) membership in March 2003 for a six-month trial period. This allowed for initial feedback from the COG membership, resulting in additional review and revision of the guidelines by the Late Effects Committee prior to public release.

#### **Revisions**

All revisions proposed by the task forces were evaluated by a panel of experts, and if accepted, assigned a score (see "Rating Scheme for the Strength of the Evidence"). Proposed revisions that were rejected by the expert panel were returned with explanation to the relevant task force chair. If desired, task force chairs were given an opportunity to respond by providing additional justification and resubmitting the rejected task force recommendation(s) for further consideration by the expert panel.

## **RECOMMENDATIONS**

#### **MAJOR RECOMMENDATIONS**

Note from the Children's Oncology Group and the National Guideline Clearinghouse (NGC): The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers (COG LTFU) are organized according to therapeutic exposures; this guideline has been divided into individual summaries. In addition to the current summary, the following are available:

- Sections 1-2: Any Cancer Experience
- Sections 3–5: Blood/Serum Products
- Sections 6–37: Chemotherapy
- Sections 38–91: Radiation
- Sections 92–106: Hematopoietic Cell Transplant
- Sections 107–132: Surgery
- Sections 133–136: Other Therapeutic Modalities

In order to accurately derive individualized screening recommendations for a specific childhood cancer survivor using this guideline, see "Using the COG LTFU Guidelines to Develop Individualized Screening Recommendations" in the <u>original guideline document</u>. (Note: For ease of use, a Patient-Specific Guideline Identification Tool has been developed to streamline the process and is included in <u>Appendix I</u> of the original guideline document.)

## **Guideline Organization**

The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers are organized according to therapeutic exposures, arranged by column as follows:

**System** Body system (e.g., auditory, musculoskeletal) most relevant to

each guideline section.

**Score** Score assigned by expert panel representing the strength of

data from the literature linking a specific late effect with a therapeutic exposure coupled with an assessment of the appropriateness of the screening recommendation based on

collective clinical experience.

**Section Number** Unique identifier for each guideline section corresponding with

listing in Index.

Therapeutic Therapeutic intervention for malignancy, including

chemotherapy, radiation, surgery, blood/serum products, hematopoietic cell transplant, and other therapeutic

modalities.

**Risk Factors** Host factors (e.g., age, sex, race, genetic predisposition),

treatment factors (e.g., cumulative dose of therapeutic agent, mode of administration, combinations of agents), medical conditions (e.g., pre-morbid or co-morbid conditions), and health behaviors (e.g., diet, smoking, alcohol use) that may

increase risk of developing the complication.

**Highest Risk** Conditions (host factors, treatment factors, medical conditions and/or health behaviors) associated with the highest risk for

**Factors** and/or health behaviors) associated with the highest risk for developing the complication.

**Periodic**Recommended screening evaluations, including health history, physical examination, laboratory evaluation, imaging, and psychosocial assessment. Recommendation for minimum frequency of periodic evaluations is based on risk factors and

magnitude of risk, as supported by the medical literature and/or the combined clinical experience of the reviewers and

panel of experts.

Health Counseling/ Further Considerations

Agent

**Health Links**: Health education materials developed specifically to accompany these guidelines. Title(s) of Health Link(s) relevant to each guideline section are referenced in this column. Health Link documents are included in <a href="#Appendix II">Appendix II</a> of the original guideline document.

**Counseling**: Suggested patient counseling regarding measures to prevent/reduce risk or promote early detection of the potential treatment complication.

**Resources**: See the original guideline document for lists of books and web sites that may provide the clinician with additional relevant information.

**Considerations for Further Testing and Intervention:** 

Recommendations for further diagnostic evaluations beyond minimum screening for individuals with positive screening tests, recommendations for consultation and/or referral, and recommendations for management of exacerbating or predisposing conditions.

# References

References are listed immediately following each guideline section in the original guideline document. Included are medical citations that provide evidence for the association of the therapeutic intervention with the specific treatment complication and/or evaluation of predisposing risk factors. In addition, some general review articles have been included in the Reference section of the original guideline document for clinician convenience.

**Note**: See the end of the "Major Recommendations" field for explanations of <u>abbreviations</u> included in the summary.

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
137 (Female)	Breast	Over age 40 Family history of breast cancer in first degree relative Early onset of menstruation Late onset of menopause (age 55 or older) Older than 30 at birth of first child Never pregnant Obesity Previous breast biopsy with atypical hyperplasia Hormone replacement therapy	Chest radiation with potential impact to the breast (see Section 68; see list of related summaries at the beginning of the "Major Recommendation" field), including ≥20 Gy to the following fields:  • Mantle • Mini-Mantle • Mediastinal • Chest (thorax) • Axilla  BRCA1, BRCA2, ATM mutation	PATIENTS AT STANDARD RISK (ACS Recommendation)  Physical  Clinical breast exam  (Every 3 years between ages 20- 39, then yearly beginning at age 40)  Screening  Mammogram (Yearly, beginning at age 40)  PATIENTS AT HIGHEST RISK  Physical  Breast self exam  (Monthly, beginning at puberty)	Health Links  See "Patient Resources" field  Breast Cancer (for patients at highest risk only)  Counseling  For patients at highest risk, counsel to perform breast self-examination monthly, beginning at puberty. For standard risk patients, provide general guidance regarding routine screening beginning at age 40 per current ACS

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
				Clinical breast	guidelines.
				(Yearly, beginning at puberty until age 25, then every six months)	Considerations for Further Testing and Intervention
				Screening	Surgery and/or oncology consultation as
				Mammogram	clinically indicated.
				(Yearly, beginning 8 years after radiation or at age 25, whichever occurs last)	
				Info Link:	
				There is currently a deficiency in the literature regarding whether or not TBI is a risk factor for the development of breast cancer.  Monitoring of patients who received TBI should be determined on an individual basis.	
				Mammography is currently limited in its ability to evaluate premenopausal breasts. The role of MRI is evolving for screening of other populations at high risk for breast cancer (e.g.,	
				premenopausal known or likely carriers of gene	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
				mutation of known penetrance).	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
(Female)	Cervical	Early age at first intercourse Multiple lifetime sex partners Smoking Sexually transmitted diseases	Personal history of cervical dysplasia Prenatal DES exposure HPV infection Immunosuppression Chronic steroid use HIV positive Chronic GVHD	PATIENTS AT STANDARD RISK (ACS Recommendation)  Physical  Pelvic exam (Every 1 to 2 years)  Screening  Cervical PAP smear  (Yearly for regular PAP test. Every 2 years for liquid- based PAP test. After age 30, if patient has had 3 consecutive normal annual PAP tests, may screen every 2-3 years [with conventional or liquid-based cervical cytology] or every 3 years [with HPV DNA test plus cervical cytology]).  Info Link:	Health Links  See "Patient Resources" field  Reducing the Risk of Second Cancers  Considerations for Further Testing and Intervention  Gynecology and/or oncology consultation as clinically indicated.

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
				Begin screening (in patients with a cervix) 3 years after first vaginal intercourse, or at age 21, whichever occurs first.	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
139	Colorectal	High fat/low fiber diet Age ≥50 years Obesity	Radiation with potential impact to the colon/rectum (see Section 78; see list of related summaries at the beginning of the "Major Recommendation" field), including ≥30 Gy to the following fields:  • Whole abdomen • All upper abdominal fields • Pelvic • Spine (thoracic, lumbar, sacral)  Personal history of ulcerative colitis,	PATIENTS AT STANDARD RISK (ACS Recommendation)  Screening  Option 1: Fecal occult blood (minimum of 3 cards)  (Yearly, beginning at age 50)  AND/OR  Flexible sigmoidoscopy  (Every 5 years, beginning at age 50)  Note: The combination of yearly fecal occult blood testing and every 5 year flexible sigmoidoscopy is	Health Links  See "Patient Resources" field  Colorectal Cancer  Considerations for Further Testing and Intervention  Gastroenterology, surgery, and/or oncology consultation as clinically indicated.

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
			gastrointestinal malignancy, adenomatous polyps, or hepatoblastoma  Familial polyposis  Family history of colorectal cancer or polyps in first degree relative	preferable to either test done alone.  Option 2: Double contrast barium enema  (Every 5 years, beginning at age 50)  Option 3: Colonoscopy  (Every 10 years, beginning at age 50)  PATIENTS AT HIGHEST RISK  Screening  Colonoscopy  (Every 5 years [minimum]; more frequently if indicated based on colonoscopy results. Begin monitoring 10 years after radiation or at age 35, whichever occurs last. Monitor more frequently if clinically indicated. Per the ACS, begin screening earlier for the following highrisk groups: HNPCC [at puberty], FAP [at age 21 years], IBD [8 years after diagnosis of IBD]. Information from the first	

Sec Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
			colonoscopy will inform frequency of follow up testing.	
			Info Link:	
			Reports of gastrointestinal malignancies in cohorts of long-term survivors suggest that radiation likely increases risk, but the median age of onset is not as well established as that of secondary breast cancer following chest radiation. The expert panel agreed that early onset of screening likely was beneficial, and that a prudent course would be to initiate screening for colorectal cancer for those at highest risk (abdominal, pelvic, and/or spinal radiation >30 Gy) at age 35, or 10 years post radiation, whichever occurs last. Surveillance should be done via colonoscopy as per recommendations for populations at highest risk, with information from the first colonoscopy informing the	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
				up testing.	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
140 (Female)	Endometrial	Obesity Older age Unopposed estrogen therapy Tamoxifen Diabetes Hypertension High fat diet Early menopause Late menopause Nulliparity Infertility Failure to ovulate	History of/at risk for HNPCC	PATIENTS AT HIGHEST RISK (ACS Recommendation)  Screening  Endometrial biopsy  (Yearly, beginning at age 35 for patients at highest risk)  Info Link:  Women at highest risk should be informed that screening recommendation of endometrial biopsy beginning at age 35 is based on expert opinion in the absence of definitive scientific evidence and the potential benefits, risks, and limitations of testing for early endometrial cancer detection should be	Health Links See "Patient Resources" field Reducing the Risk of Second Cancers

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
141	Lung	Smoking Workplace exposures to asbestos, arsenic, radiation	Chest radiation with potential impact to the lung	PATIENTS AT HIGHEST RISK History	Health Links  See "Patient Resources" field  Reducing the Risk of Second Cancers
	Second hand smoke (in non- smokers)		Cough Wheezing SOB	Considerations for Further Testing and Intervention	
				(Yearly, and as clinically indicated)	Imaging and surgery and/or oncology consultation as clinically indicated.
				Physical Pulmonary Exam (Yearly, and as clinically indicated)	

 $oldsymbol{Note}:$  See a list of  $\underline{Abbreviations}$  at the end of the "Major Recommendations" field.

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
142	Oral	Tobacco use (smoking cigars, cigarettes, or pipes; dipping, chewing) Alcohol abuse Excessive sun exposure (increases risk	Head/brain radiation Neck radiation TBI Acute/chronic GVHD	PATIENTS AT HIGHEST RISK  Physical Oral cavity exam	Health Links  See "Patient Resources" field  Reducing the Risk of Second Cancers Dental Health  Considerations for

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
		of cancer of lower lip) HCT (allogeneic > autologous)		(Yearly)	Further Testing and Intervention  Head and neck/otolaryngology consultation as indicated.

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
143 (Male)	Prostate	Older age, with steadily increasing risk after age 40 years.	African- American race Family history of prostate cancer in first degree relative	Clinicians should be prepared to discuss prostate cancer testing with patients  Info Link:  The USPSTF found good evidence that PSA screening can detect early-stage prostate cancer but mixed and inconclusive evidence that early detection improves health outcomes. Screening is associated with important harms, including frequent false-positive results and unnecessary anxiety, biopsies, and potential complications of treatment of some	Health Links  See "Patient Resources" field  Reducing the Risk of Second Cancers  Considerations for Further Testing and Intervention  Urology and/or oncology consultation as clinically indicated.

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
				cancers that may never have affected a patient's health. The USPSTF concludes that evidence is insufficient to determine whether the benefits outweigh the harms for a screened population. ACS concurs with this conclusion.	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
144	Skin	Light skin color Chronic exposure to sun Atypical moles or ≥50 moles	Any history of radiation Personal history of melanoma or skin cancer Dysplastic nevi Family history of melanoma or skin cancer History of severe sunburn at young age	PATIENTS AT STANDARD RISK  Info Link:  The USPSTF concludes that the evidence is insufficient to recommend for or against routine screening for skin cancer using a total-body skin examination for the early detection of cutaneous melanoma, basal cell cancer, or squamous cell skin cancer. There are no randomized trials or case-control studies that directly examine whether screening by clinicians	Health Links  See "Patient Resources" field  Reducing the Risk of Second Cancers Skin Health  Considerations for Further Testing and Intervention  Surgery, dermatology, and/or oncology consultation as clinically indicated.

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
				is associated with improved clinical outcomes such as reduced morbidity or mortality from skin cancer. No studies were found that evaluated whether screening improves the outcomes of these cancers. The ACS recommends skin examination as part of a cancer-related checkup, which should occur on the occasion of the patient's periodic health examination. Self-examination of skin is recommended once a month.	
				PATIENTS AT HIGHEST RISK	
				Physical	
				Skin self exam (Monthly)	
				Dermatologic exam with attention to skin lesions and pigmented nevi in radiation field	
				(Yearly)	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
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Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
145 (Male)	Testicular	Young males	History of cryptorchidism History of testicular cancer or carcinoma insitu in contralateral testis History of gonadal dysgenesis Klinefelter's syndrome Family history of testicular cancer	Info Link:  For standard and high risk populations, the USPSTF recommends against routine screening for testicular cancer in asymptomatic adolescent and adult males. In 2004, the USPSTF found no new evidence that screening with clinical examination or testicular self-examination is effective in reducing mortality from testicular cancer. Even in the absence of screening, the current treatment interventions provide very favorable health outcomes. Given the low prevalence of testicular cancer, limited accuracy of screening tests, and no evidence for the incremental	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
				benefits of screening, the USPSTF concluded that the harms of screening exceed any potential benefits. ACS also no longer recommends clinical testicular cancer screening or testicular self-examination.	

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counse
146	General Health Screening		Factors	Screening  Refer to USPSTF recommendations at www.ahrq.gov/clinic/uspstfix.htm  (Yearly)	Considerations for Furt Childhood cancer survivor maintenance per standard Recommended preventive screening for hypertensio alcohol misuse. In additio screening for lipid disorded diabetes mellitus. Others prevention of cardiovascu disorders. See <a href="https://www.cdc.gov/vacci">www.ahrq.</a> recommendations.  Assess immunization statindicated. See <a href="http://www.cdc.gov/vacci">http://www.cdc.gov/vacci</a>
					current immunization sch For all HCT patients, reim (http://www.cdc.gov/mm see table 4) or EBMT Guid

Sec #	Organ	At Risk Population	Highest Risk Factors	Periodic Evaluation	Health Counse
					(http://www.nature.com/

**Note**: See a list of <u>Abbreviations</u> at the end of the "Major Recommendations" field.

#### **Abbreviations**

- ACS, American Cancer Society
- ATM, ataxia telangiectasia cancer susceptibility gene located on chromosome
   11
- BRCA1, breast cancer early onset gene (cancer susceptibility gene located on chromosome 17)
- BRCA2, breast cancer 2 early onset gene (cancer susceptibility gene located on chromosome 13)
- CDC, Centers for Disease Control and Prevention
- DES, diethylstilbestrol
- DNA, deoxyribonucleic acid
- DOE, dyspnea on exertion
- EBMT, European Group for Blood and Marrow Transplantation
- FAP, familial adenomatous polyposis
- GVHD, graft versus host disease
- Gy, gray
- HCT, hematopoietic cell transplant
- HIV, human immunodeficiency virus
- HNPCC, hereditary nonpolyposis colorectal cancer
- HPV, human papilloma virus
- IBD, inflammatory bowel disease
- MRI, magnetic resonance imaging
- PAP, Papanicoulau
- PSA, prostate specific antigen
- SOB, shortness of breath
- TBI, total body irradiation
- USPSTF, United States Preventive Services Task Force

# **CLINICAL ALGORITHM(S)**

None provided

## **EVIDENCE SUPPORTING THE RECOMMENDATIONS**

## TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting the recommendations is not specifically stated.

## BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

## **POTENTIAL BENEFITS**

Potential benefits of implementing these guidelines into clinical practice include earlier identification of and intervention for late onset therapy-related complications in this at-risk population, potentially reducing or ameliorating the impact of late complications on the health status of survivors. In addition, ongoing healthcare that promotes healthy lifestyle choices and provides ongoing monitoring of health status is important for all cancer survivors.

## **POTENTIAL HARMS**

Potential harms of guideline implementation include increased patient anxiety related to enhanced awareness of possible complications, as well as the potential for false-positive screening evaluations, leading to unnecessary further workup. In addition, costs of long-term follow-up care may be prohibitive for some patients, particularly those lacking health insurance, or those with insurance that does not cover the recommended screening evaluations.

## **QUALIFYING STATEMENTS**

## **QUALIFYING STATEMENTS**

- The information and contents of each document or series of documents made available by the Children's Oncology Group relating to late effects of cancer treatment and care or containing the title "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers" or the title "Health Link," whether available in print or electronic format (including any digital format, e-mail transmission, or download from the website), shall be known hereinafter as "Informational Content." All Informational Content is for informational purpose only. The Informational Content is not intended to substitute for medical advice, medical care, diagnosis, or treatment obtained from a physician or healthcare provider.
- To cancer patients (if children, their parents or legal guardians): Please seek the advice of a physician or other qualified healthcare provider with any questions you may have regarding a medical condition and do not rely on the Informational Content. The Children's Oncology Group is a research organization and does not provide individualized medical care or treatment.
- To physicians and other healthcare providers: The Informational Content is
  not intended to replace your independent clinical judgment, medical advice,
  or to exclude other legitimate criteria for screening, health counseling, or
  intervention for specific complications of childhood cancer treatment. Neither
  is the Informational Content intended to exclude other reasonable alternative
  follow-up procedures. The Informational Content is provided as a courtesy,
  but not intended as a sole source of guidance in the evaluation of childhood
  cancer survivors. The Children's Oncology Group recognizes that specific
  patient care decisions are the prerogative of the patient, family, and
  healthcare provider.
- While the Children's Oncology Group has made every attempt to assure that the Informational Content is accurate and complete as of the date of

- publication, no warranty or representation, express or implied, is made as to the accuracy, reliability, completeness, relevance, or timeliness of such Informational Content.
- No liability is assumed by the Children's Oncology Group or any affiliated party or member thereof for damage resulting from the use, review, or access of the Informational Content. You agree to the following terms of indemnification: (i) "Indemnified Parties" include authors and contributors to the Informational Content, all officers, directors, representatives, employees, agents, and members of the Children's Oncology Group and affiliated organizations; (ii) by using, reviewing, or accessing the Informational Content, you agree, at your own expense, to indemnify, defend and hold harmless Indemnified Parties from any and all losses, liabilities, or damages (including attorneys' fees and costs) resulting from any and all claims, causes of action, suits, proceedings, or demands related to or arising out of use, review or access of the Informational Content.
- Ultimately, as with all clinical guidelines, decisions regarding screening and clinical management for any specific patient should be individually tailored, taking into consideration the patient's treatment history, risk factors, comorbidities, and lifestyle. These guidelines are therefore not intended to replace clinical judgment or to exclude other reasonable alternative follow-up procedures. The Children's Oncology Group recognizes that specific patient care decisions are the prerogative of the patient, family, and healthcare provider.

## **IMPLEMENTATION OF THE GUIDELINE**

#### **DESCRIPTION OF IMPLEMENTATION STRATEGY**

Implementation of these guidelines is intended to standardize and enhance followup care provided to survivors of pediatric malignancies throughout the lifespan. Considerations in this regard include the practicality and efficiency of applying these broad guidelines in individual clinical situations. Studies to address guideline implementation and refinement are a top priority of the Children's Oncology Group (COG) Late Effects Committee, and proposals to study feasibility of guideline use in limited institutions are currently underway. Issues to be addressed include description of anticipated barriers to application of the recommendations in the quidelines and development of review criteria for measuring changes in care when the guidelines are implemented. Additional concerns surround the lack of current evidence establishing the efficacy of screening for late complications in pediatric cancer survivors. While most clinicians believe that ongoing surveillance for these late complications is important in order to allow for early detection and intervention for complications that may arise, development of studies addressing the efficacy of this approach is imperative in order to determine which screening modalities are optimal for asymptomatic survivors.

In addition, the clinical utility of this lengthy document has also been a top concern of the COG Late Effects Committee. While recognizing that the length and depth of these guidelines is important in order to provide clinically-relevant, evidence-based recommendations and supporting health education materials, clinician time limitations and the effort required to identify the specific recommendations relevant to individual patients have been identified as barriers to their clinical application. Therefore, the COG Late Effects Committee is currently

partnering with the Baylor School of Medicine in order to develop a web-based interface, known as "Passport for Care," that will generate individualized exposure-based recommendations from these guidelines in a clinician-focused format for ease of patient-specific application of the guidelines in the clinical setting. As additional information regarding implementation of the Passport for Care web-based interface becomes available, updates will be posted at www.survivorshipquidelines.org.

#### **IMPLEMENTATION TOOLS**

Chart Documentation/Checklists/Forms
Patient Resources
Resources

For information about <u>availability</u>, see the "Availability of Companion Documents" and "Patient Resources" fields below.

# INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

## **IOM CARE NEED**

Living with Illness Staying Healthy

## **IOM DOMAIN**

Effectiveness Patient-centeredness

## **IDENTIFYING INFORMATION AND AVAILABILITY**

## **BIBLIOGRAPHIC SOURCE(S)**

Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 137-146: cancer and general health screening. Bethesda (MD): Children's Oncology Group; 2006 Mar. 11 p. [45 references]

#### **ADAPTATION**

Not applicable: The guideline was not adapted from another source.

#### **DATE RELEASED**

2003 Sep (revised 2006 Mar)

## **GUIDELINE DEVELOPER(S)**

Children's Oncology Group - Medical Specialty Society 23 of 26

## **SOURCE(S) OF FUNDING**

This work was supported by the Children's Oncology Group grant U10 CA098543 from the National Cancer Institute.

## **GUIDELINE COMMITTEE**

Children's Oncology Group Nursing Discipline and Late Effects Committee

## **COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE**

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## FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

All Children's Oncology Group (COG) members have complied with the COG conflict of interest policy, which requires disclosure of any potential financial or other conflicting interests.

## **GUIDELINE STATUS**

This is the current release of the guideline.

This guideline updates a previous version: Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 1.2. 2004 Mar.

## **GUIDELINE AVAILABILITY**

Electronic copies: Available in Portable Document Format (PDF) from the <u>Children's Oncology Group Web site</u>.

## **AVAILABILITY OF COMPANION DOCUMENTS**

The following are available:

- Instructions for use. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March. 6 p.
- Introductory material. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March. 9 p.
- Summary of cancer treatment. Appendix I: Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March.
- Patient-specific guideline identification tool. Appendix I: Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers.
   Version 2.0. Children's Oncology Group. 2006 March.

Electronic copies: Available in Portable Document Format (PDF) from the Children's Oncology Group Web site.

## **PATIENT RESOURCES**

In an effort led by the Nursing Clinical Practice Subcommittee, complementary patient education materials (*Health Links*) were developed and are available in Appendix II of the original guideline document. The following Health Links are relevant to this summary:

## Section 137

Breast Cancer

## Sections 138, 140, 141, 142, 143, 144

Reducing the Risk of Second Cancers

#### Section 139

Colorectal Cancer

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

## **NGC STATUS**

This NGC summary was completed by ECRI Institute on May 11, 2007. The information was verified by the guideline developer on June 11, 2007.

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